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Sleeping is a nightmare: A qualitative study on the experience and management of poor sleep quality in women with fibromyalgia

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Abstract

Aim: This study aimed to explore the experience and management of poor sleep quality in Spanish women with fibromyalgia (FM).

Design: This was a qualitative study based on one-to-one interviews.

Methods: Twenty-one adult women diagnosed with FM were recruited from the community between January and March 2020. Data were collected through in-depth semistructured one-to-one interviews, using an interview guide of open questions about the experience and management of poor sleep quality, and were analyzed with thematic qualitative analysis. The symptom management theory was used as a biopsychosocial conceptual framework.

Results: The results were organized into two themes: (a) experience of poor sleep quality and (b) management strategies for poor sleep quality. Poor sleep quality was found to be a severe symptom of FM that negatively impacts pain, fatigue, stiffness, mental health, and quality of life. The participants perceived pharmacological treatment to be the main approach of health care professionals for improving sleep, and most did not want this form of treatment. Self-management strategies lack clear beneficial effects on sleep quality.

Conclusion: Women with FM recognize that they need to receive more information from nurses and allied professions about sleep in the context of FM and how to effectively manage poor sleep quality.

Impact: This study contributes to a better understanding of how women with FM experience and manage poor sleep quality. More information about management strategies for poor sleep quality from nurses and other health care professionals is needed in women with FM. The results of this study can be applied by nurses and health care professionals, including sleep educators, in the treatment of this patient group.

KEYWORDS
fibromyalgia, nursing, poor sleep quality, qualitative research, symptom management theory

1 | INTRODUCTION

Fibromyalgia (FM) is a chronic health condition classified as a central sensitivity syndrome. FM is characterized by chronic multisite pain and other complaints such as tenderness, fatigue, poor sleep quality, impaired functionality, and poor quality of life (Arnold et al., 2016).

Together with pain and fatigue, poor sleep quality is considered a core symptom in the diagnosis of FM (Arnold et al., 2019) with approximately 90% of patients reporting this symptom (Andrade et al., 2018). Poor sleep quality negatively impacts physical, emotional, and cognitive factors related to FM, such as pain intensity (Certal & Domingues, 2018; Keskindag & Karaaziz, 2017; Mun et al., 2020), depression (Certal & Domingues, 2018; Keskindag & Karaaziz, 2017), fatigue (Roth et al., 2016), and pain catastrophizing (Mun et al., 2020).

To date, no curative treatments are available, and efforts by health providers should be focused on providing treatment approaches that facilitate the development of effective self-management strategies to alleviate the symptoms of FM, including poor sleep quality (Turk & Adams, 2016). The most recent clinical guidelines of the European League Against Rheumatology (EULAR) (Macfarlane et al., 2017) pointed out that treatments and recommendations for FM should be patient-centered and adapted to the specific needs of each patient, being the nonpharmacological approaches the most recommended. Bair and Krebs (2020) recently stressed the relevance of including sleep management in the initial treatment of FM including patient education and self-management strategies as the main approaches. However, poor sleep quality continues to remain an underrepresented issue in chronic pain management programs (Tang et al., 2015).

In order to provide sleep education and recommendations for self-management strategies, it could be important to understand how people diagnosed with FM experience poor sleep quality, not only by exploring the meaning of the symptom but also how they manage it and their perspectives on prescribed treatments. In this sense, qualitative research methods could be valuable in producing a different and complementary knowledge to quantitative approaches. Qualitative research could produce a more nuanced understanding of the experience of poor sleep quality in the context of FM that could help in developing educational materials and management strategies based on the needs and preferences of the patients.

1.1 | Background

Fibromyalgia is a chronic health condition that affects approximately 2% of the world's population and 2.64% of the population in Europe (Heidari et al., 2017). In Spain, the prevalence of FM is estimated to be 2.4% among the adult population, and its related direct and indirect costs are approximately 13 billion euros per year (Cabo-Meseguer et al., 2017). FM is mainly diagnosed in middle-aged women, accounting for up to 90% of the cases (Wolfe et al., 2018).

Poor sleep quality is a prominent symptom, and the main sleep problems described for this condition include reduced sleep efficiency, long wake times after sleep onset, a decrease in the percentage of deep sleep, and an increased percentage of light sleep (Andrade et al., 2018; Lawson, 2020; Rizzi & Cristiano, 2016; Roth et al., 2016; Wu et al., 2017).

According to Buysse et al., (1989), objective measures should never be the basis for defining sleep quality, as it is a predominantly subjective construct. Kline (2013) defined poor sleep quality as "one's satisfaction of the sleep experience, integrating aspects of sleep initiation, sleep maintenance, sleep quantity, and refreshment upon awakening." Based on this definition, it can be inferred that the meaning of poor sleep quality can be different from one person to another. For instance, for a person with difficulties falling asleep that would be the main factor for defining poor sleep quality while for another person, it may be the difficulty maintaining sleep throughout the night.

Qualitative research methods can inform nurses and allied health care professionals for the development of evidence-based clinical practice. Qualitative results are usually easily applicable in the clinical practice of nurses because it enables the understanding of a phenomenon from the perspective of the patients, which is essential for providing proper nursing care (Broeder & Donze, 2010). Also, consistency between the provided healthcare and the individual needs, preferences, and values is essential for the treatment to be effective (Salmond, 2007).

Although poor sleep quality is a common concern in people diagnosed with FM (Cunningham & Jillings, 2006; Lempp et al., 2009; Sallinen et al., 2011), a recently published meta-summary and meta-synthesis by our research team (Climent-Sanz, Morera-Amenós, et al., 2020) showed that the experience of poor sleep quality in the context of FM is an underexplored topic in the available qualitative research and that only one study focused exclusively on the construct of sleep (Theadom & Cropley, 2010). In addition, most of the studies described almost exclusively how people diagnosed with FM evaluate the symptom, and little information was provided regarding the response to the symptom, the self-management strategies developed to cope with it, and the perspective on prescribed treatments. This is why we considered it relevant to carry out a qualitative inquiry that helped to understand the experience of poor sleep quality in the context of FM.

1.2 | The Symptom Management Theory as a conceptual framework

The symptom management theory (SMT) (Humphreys et al., 2014) was adopted as the study's conceptual framework. The SMT is a middle-range theory that can be applied to both clinical practice and research to guide the assessment of the experience of symptoms and to develop management strategies. The theory is based on the assumption that the symptom management process is dynamic and multidimensional, and it is organized into three interconnected dimensions: (a) symptom experience, (b) symptom management strategies, and, (c) outcomes. In order for the symptom experience dimension to be comprehensively explored, it is further divided into three subdimensions: perception, evaluation, and response. The symptom management strategies dimension is used to assess how symptoms are treated and/or managed, and the outcomes dimension is used to assess functional and emotional status, quality of life, self-care, costs, mortality, and morbidity in order to analyze the effects of management strategies.

To our knowledge, this is the first qualitative study taking the SMT as a conceptual framework to explore and describe how women diagnosed with FM experience poor sleep quality from a biopsychosocial perspective. The choice of the SMT as a conceptual framework was based on the premise that the current treatment approaches for FM are symptom-focused and aim at achieving a successful self-management of the symptoms. Therefore, the dimensions and the concepts nested within the SMT could help in identifying and describing key aspects of the experience of poor sleep quality that may serve in informing nurses and other health care providers for the development of management strategies that help people suffering from FM to effectively self-cope with this symptom.

2 | THE STUDY

2.1 | Aim

To explore the experience and management strategies for poor sleep quality in adult women diagnosed with FM.

2.2 | Design

A qualitative study belonging to a wider research project (Climent-Sanz, Gea-Sánchez, et al., 2020).

2.3 | Participants

The participants were 21 adult women, with the ability to understand and speak Spanish and/or Catalan, and with a diagnosis of FM by rheumatologists based on the 2016 criteria of the American College of Rheumatology (Wolfe et al., 2016). A theoretical sample was previously defined to reach heterogeneity among participants, taking into account the following pre-established criteria: age, educational level, employment status, civil status, and participation or not in FM associations. Participants were recruited from the FM association FibroLleida and the Primary Health Care Centre Onze de Setembre, located in the city of Lleida (Catalonia, Spain). Two gatekeepers from both institutions directly invited women to participate and facilitated a list of women interested in participating in the study. The first author contacted the women by phone and, after explaining the objectives and procedures of the study, they established an appointment at the University or a medical consultation of the Primary Health Care Centre. We stopped recruiting participants when data saturation was reached.

2.4 | Data collection

Data were collected using in-depth semistructured personal interviews, following an interview guide of open questions about the experience and management of poor sleep quality. The interview guide (Table 1) was developed based on two of the domains of the SMT "Symptom Experience" and "Symptom Management Strategies," and integrating the concepts nested within said domains. To explore the experience of poor sleep quality, the questions were developed considering the concepts of evaluation and response nested within the "Symptom Experience" domain. Evaluation is understood as the meaning that a person attributes to the experienced symptom/s in terms of effects, severity, temporality, cause, and treatability (Humphreys et al., 2014). Regarding the questions related to the management of poor sleep quality, we

TABLE 1 Interview guide.

1. What does it mean for you to sleep well or have a good sleep quality?
2. Could you tell me what a night of yours is like from the moment you go to bed to the moment you get up?
3. When you don't sleep well one night, what do you usually think?
4. What do you think can happen to you in the future if you continue to sleep poorly?
5. What worries you most about your sleep?
6. What have health professionals explained to you about sleep in the context of fibromyalgia?
7. What do you think is the origin or the cause of your poor sleep quality?
8. What advice have health professionals given you to help you sleep better?
9. What do you do when you lie down and can't sleep?
10. What do you do when you wake up in the middle of the night and find it hard to go back to sleep?
11. What do you do when you wake up too early?
12. The day after a bad night's sleep, what do you usually do to deal with the consequences?
13. Why do you think you continue to have sleep problems despite the advice of healthcare professionals and having developed your own management strategies?
14. If you had a chance to talk to the world's greatest sleep expert, what would you ask him/her?

explored the strategies developed by the participants and the ones prescribed by health care providers. In addition, the participants were also asked about their perception regarding the effects of both the self-management strategies and the prescribed ones on sleep quality. The interview was flexible, allowing the exploration of new paths that arose spontaneously and providing the opportunity to deepen into topics that were not considered at first (Doody & Noonan, 2013).

The interviews were carried out by two researchers (CCS and MGS) in a private office at the Faculty of Nursing and Physiotherapy of the University of Lleida or in a medical consultation of the primary health center Onze de Setembre between January and March 2020. The interviews lasted between 30 and 55 minutes.

2.5 | Ethical considerations

This study followed the principles of the Declaration of Helsinki and the Belmont Report. Approval was obtained from the ethics committee of "Hospital Universitari Arnau de Vilanova" (Code CEIC-1999). Prior to data collection, participants were provided oral and written information about the project, and they had the opportunity to ask any doubts or questions regarding the project. They voluntarily participated after signing written informed consent.

2.6 | Data analysis

All interviews were digitally recorded and transcribed verbatim. Both interview transcripts and field notes capturing participants' nonverbal responses were imported into the NVivo 12 qualitative analysis software to help organize the information.

A thematic qualitative analysis was conducted guided by the SMT developed by Humphreys et al., (2014). In accordance with the SMT, the results were organized around two pre-established themes corresponding to the domains of "Symptom Experience" and "Symptom Management Strategies" and the subthemes were established according to the factors nested within each of the domains.

CCS and EBV assigned emerging open codes to sentences of the transcriptions, summarizing their meaning, and created groups of codes according to their similar meaning. After putting in common their analysis, they classified those groups of codes under pre-established subthemes (Braun & Clarke, 2006).

2.7 | Rigor

The rigor of the study was ensured by following the COREQ EQUATOR guidelines, and by applying the trustworthiness criteria for qualitative research following Lincoln and Guba (1985). To reach dependability, the entire process has been documented and detailed in the description of the methodology, and an emergent design was followed: data collection and analysis were conducted in parallel, and researchers were able to introduce changes during the process. Interviews with women were conducted until data was saturated, and the context was described to the readers to decide if the results could be transferable to other similar settings. To enhance credibility, the analysis was triangulated by two independent researchers (JTMG and MGS). Confirmability of the results has been guaranteed by including literal quotes of the participants support the interpretation of results, and the entire work process was supervised by different members of the team not directly involved in the analysis of results.

3 | FINDINGS

The study participants ranged in age from 44 to 75 years. The characteristics of the participants are presented in Table 2.

The results were organized into two themes: experience of poor sleep quality and management strategies for poor sleep quality. Subthemes and categories, and participant comments are presented in Tables 3 and 4, respectively.

3.1 | Experience of Poor sleep quality

3.1.1 | Evaluation of poor sleep quality

Main sleep problems

Women with FM complained about not being able to sleep for more than 5–6 hours at a time, waking up several times during the night. Then, participants felt that they did not have a recovering sleep.

They would wake up after a very short period of time asleep and have difficulty falling asleep again. Participants reported waking up during the night feeling pain (in any body part, such as the arms and hands), experiencing light sleep, and feeling the need to visit the toilet.

They also mentioned having difficulty falling asleep at night and even being unable to sleep for days.

It was common among participants to relate their difficulty falling asleep with being very sensitive to noise. Women with FM experienced other difficulties in falling asleep, such as finding a comfortable body position free of pain.

The women mentioned that their sleep problems fluctuated: there were nights in which their main problem was that they had difficulty falling asleep and other night in which they would wake up several times during the night. One participant thought that the variability in her sleep problems made it difficult for her to find an effective solution to improve her sleep.

Aggravating factors of poor sleep quality

The participants reported that menopause-related hot flashes and other comorbidities (e.g., restless leg syndrome, sleep apnea, and tinnitus) prevented them from falling asleep or produce awakenings

TABLE 2 Characteristics of the participants (N = 21).

Participant	Age	Educational level	Employment status	Civil status	Member of FM association
1	53	Secondary	Full-time employment	Registered partner	No
2	59	Tertiary	Medically retired	Married	Yes
3	72	Primary	Retired	Married	No
4	61	Secondary	Retired	Married	No
5	68	Primary	Retired	Married	No
6	56	Primary	Part-time employment	Divorced	No
7	65	Secondary	Retired	Married	No
8	61	Secondary	Full-time employment	Divorced	No
9	66	Secondary	Part-time employment	Divorced	No
10	45	Tertiary	Full-time employment	Married	No
11	68	Secondary	Retired	Married	No
12	58	Primary	Full-time employment	Divorced	No
13	59	Secondary	Medically retired	Registered partner	No
14	59	Primary	Medically retired	Registered partner	No
15	44	Secondary	On sick leave	Married	Yes
16	54	Secondary	Medically retired	Married	Yes
17	61	Secondary	Medically retired	Divorced	Yes
18	55	Secondary	Full-time employment	Married	Yes
19	44	Secondary	Medically retired	Divorced	Yes
20	75	Primary	Retired	Married	Yes
21	67	Primary	Retired	Married	Yes

during the night. They also commented that the quality of their sleep was worse on days in which they engaged in less physical activity.

Factors that positively influence sleep

The participants also identified factors that favored the reconciliation of sleep or facilitated better sleep at night. These factors included to get tired during the day, to sleep in a place without noise (for example, another house in a quiet place) or on vacation not having to work or get up early.

Perspectives on good sleep quality

The participants described good sleep as waking up feeling refreshed and energized. Although some considered getting 8 hours of sleep per night beneficial, the group generally considered it more important to wake up feeling like they had obtained restful and uninterrupted sleep (even if they had only slept for 3 or 4 hours).

They considered a good night's sleep to be a night of sleep without experiencing pain during the night and waking up without pain. For example, one participant indicated that for her, a good night's sleep would be waking up in the morning without thinking to herself, "even my soul hurts" (P7). Participants also commented that good sleep involved falling asleep rapidly, forgetting about the problems of daily life and feeling peaceful, and waking up with a clear mind, which they described as feeling as if they were disconnected or not remembering what they had dreamt.

Beliefs regarding the causes of poor sleep quality

The participants identified pain, FM itself, aging, genetic factors, stress, and mental health problems (such as depression or obsessive thinking) as the main causes of poor sleep quality. In terms of temporality, they mentioned that the initiation of their sleep problems or changes in sleep patterns from deep to light sleep coincided with maternity, menopause, and periods characterized by work overload and problems with their partner. However, there were also participants who did not relate their sleep problems to a specific cause.

Consequences of poor sleep quality

Complaints related to poor sleep quality among the interviewed women included waking up feeling fatigued, stiffness, pain, mood alterations, and attention and concentration difficulties. One participant reported waking up feeling as if she had been "run over by a truck" (P14). Participants emphasized that they felt tired all throughout the day and that even performing simple tasks required great effort. They mentioned that after a bad night's sleep, they experience more intense pain, which also affected their functional capacity. Likewise, they reported that coping with pain becomes more difficult after not having a restful sleep. The women also reported waking up feeling as if their whole body were completely stiff and having to stretch for a while before being able to get out of the bed.

Poor sleep quality was perceived as being directly associated with mood alterations, as the participants felt very nervous and emotional.

TABLE 3 Theme 1. Experience of poor sleep quality.

Subtheme	Category	Quotations
Evaluation of poor sleep quality	Main sleep problems	"I never sleep, never ever, I never sleep the whole night, never ever" (P8) "I go to sleep around 10:30p.m. or 11:00 p.m. and I am always waking up. And after 12:30–3:00a.m. I no longer sleep" (P16) "The problem is that I wake up, the problem is that when I sleep, I don't sleep. I am sleeping, but it is as if I am awake" (P11) "There are times when my problem is that I can't sleep. And other times the problem is that I wake up" (P15) "I didn't know how to place myself, because if I would place myself like this my shoulder would hurt, if I would place myself like this… my hip would hurt, and you go around and around" (P16) "Sometimes because of the arms and hands, because of the pain. And other times I go to the bathroom" (P6)
	Poor sleep quality aggravating factors	"When you are silent is when you hear them (the tinnitus) the most. Then this… and of course, if you wake up at two and you have this, it is very difficult to go back to sleep" (P11) "Now I have realized that, if I am not tired and have a more active day, I also sleep worse" (P14)
	Poor sleep quality attenuating factors	"I sleep better in the village, there is no noise" (P14)
	Meaning of good sleep quality	"Getting up in the morning and feeling rested, I do not care about the hours, at least open my eyes and say, "I have slept, I feel rested, come on, let's start the day" (P15) "That you can wake up without any pain, this would be good for me… the best" (P20) "That you do not remember what you have dreamed about, that you do not remember anything and get up and say: I feel so rested, I got up feeling so well!" (P7)
	Beliefs about the origin of poor sleep quality	"[…] everything happened more or less when my period stopped, and so I said, "This is menopause". Sometimes you say, "This must be caused by the menopause"… you always look for the solution or attribute the problem to something else, yes" (P20)
	Consequences of poor sleep quality	"it is that you wake up in the morning already with fatigue that looks like you have been run over by a truck, and you cannot handle your life. You get up already holding on to the wall. And you say: I am going to get dressed, I am going to go out and I think: where am I going, if I just can't?" (P14) "In the morning everything is stiff, when I wake up, I am like a stick, all stiff" (P15) "Then you get up and you [feel]… super sore, like you have been beaten up, with a stick, that's how I got up" (P19) "I think I am very hysterical, and I answer back, and I was not like that before. I get upset over nothing, I answer badly, which I never did before, and now I do" (P3) "Sometimes I have to do like this (rubs the eyes) because I feel that my eyes… I am not clear. And, with the car, I already had a couple of scares […] the other day I almost caught a guy on a motorcycle and that scared me" (P15) "[…] there is nothing constant, it may be normal one day, and another day I can feel very tired or very nervous. The next night, I may sleep, or I may not sleep again… It changes every night, there is nothing constant" (P9)
Response to poor sleep quality	Worries, nocturnal intrusive thoughts and rumination	"I'll be sleepy, that's what I think. I do think about it because I know that tomorrow… it will be hard for me to get up" (P6) "And I say, "How strange! Why don't you sleep?" Then I wonder if I had a coffee or a drink at noon that day, "Well, that's it" (P5) "Sometimes I fall asleep quickly, but if I have occasional concerns, like everyone else, that sleepless night will catch you" (P8)
	Desperation and anticipation of poor sleep quality	"I would go to the balcony at night when I could not sleep, and say: "and from here down, four floors, I would come down in a huff and puff!" I have thought about it many times" (P7) "How are you going to start your dream? How are you going to cope with sleeping today? It was torture for me to go to sleep because I knew that I would have nightmares, I would have aches that I could not sleep at all… […] Initially, before going to sleep, I was already worried about what was going to happen to me in the dream" (P13)
	Future expectations	"[I fear] that I will go a little crazy, that I will go a little crazy, because not sleeping gives you a lot of problems, gives you a lot of anxiety, you do not live your life with peace of mind, you have a very bad temper, and then it gives me the feeling that my whole body is trembling" (P11)

TABLE 4 Theme 2. Poor sleep quality management strategies.

Subtheme	Category	Quotations
Management strategies provided by health care professionals	Health care professional's explanations about sleep in the context of fibromyalgia	"They haven't explained anything else to me, all I know is through the computer" (P9)
	Self-management advice from health care professionals	"Well, you may have been advised to try not to eat too much or not to eat too much at night [...] if you want to read, do it on the sofa, don't go to bed [...] If I do that [...] on the way from the sofa to the bed, I would lose my sleep. Everyone is different. So, each one of us must have our own tactics" (P12)
	Pharmacological treatment as the main approach	"Now I am already taking Zolpidem, I do not sleep, I pass out for a while. Four hours, I am gone, that's it [...] once I fall asleep, I stay asleep, I say, rest the body I [...] I am rested, because with other medicines, with other drugs that I have taken, I could not sleep" (P18) "(with the tablet) It usually takes me half an hour to fall asleep. And I cannot be without it (...) I want the medication to take away my anxiety, my fears and to be able to fall asleep" (P13) "I took valerian, and nothing happened, and then I took a tablet of these and after three hours I was exhausted, it was when I had to get up that I got sleepy" (P12) "I think that if I take it, it hurts me even more. Not in terms of sleep, but I feel worse. [...] And it is horrible. You are full of drugs, it is not you, you are a vegetable. No, no, not this, and on top of that, you also feel bad. They take away a... I don't know what they take, but they put you to sleep, but to sleep, you'd better die now" (P3) "You get used to the drugs and after a while they no longer work" (P9) "I'm telling you, so much medication in my body, that's what I think that will affect me in the long run" (P15)
Self-management strategies	General strategies to improve sleep quality	"If I am not tired, for spending all day without much activity, I also sleep worse. So, I try to get a little more tired [...] to get physically tired helps me. I do not take a nap, I cannot sleep. If I take a nap, then at night I do not sleep at all, for sure" (P14) "Sometimes I try to sleep thinking that I'm resting. Sometimes I try not to sleep, to sleep more at night. Nothing is constant, neither one nor the other helps me [...] There are days when one thing works for me but then the next day I am no longer doing well. There are periods when I feel better [...] A week goes by and gets terrible again" (P9)
	Strategies to fall asleep and to deal with interrupted sleep or waking up too early	"I stay there, I go around or whatever, but I stay there. I say wait, I close my eyes, I do not think about anything, to see if I fall asleep. I try to relax so that I can fall asleep" (P6) "I play with the computer and they already told me that I shouldn't do it because this is bad for sleeping" (P11) "I don't go to sleep before one [...] I don't want to go at eleven or twelve because then I would already be awake at three or four" (P17)
	Coping with the consequences of poor sleep quality during the day	"And you say "I can go and lay down"; I have to lay down because if I don't, I can't stand it, and sometimes I leave them food and go to lay down because my body can't stand it, and you say "But I can lay down and take a little nap, hopefully", and when I see that my husband stays there, sometimes I say "Wake up, I can't" (P16) "I do nothing, I remain the same, I have not slept because I have not slept, life remains the same, I continue with my life the same way" (P7)
	Needs	"I would say that it would be like a fantasy to be able to sleep well, because I sleep very badly" (P18) "[I would need] something to help me sleep and not wake up at night, those eight hours a day, so that I could sleep more comfortably" (P6)

They reported getting upset easily. They also indicated that poor sleep quality affected their executive functions, perceiving a decreased capacity for attention and concentration. They believed that poor sleep quality affected their general health status and quality of life. Furthermore, they felt that the consequences of poor sleep quality were unpredictable and did not follow a consistent pattern.

3.1.2 | Responses to poor sleep quality

Worries, nocturnal intrusive thoughts, and ruminations

Participants reported being concerned about not sleeping, especially if they were required to work the next day. When experiencing problems falling asleep, they would start analyzing their diurnal behaviors to determine what was impairing their sleep, such as drinking coffee after noon or feeling more nervous than usual. Having intrusive, recurring, and even irrational thoughts when they went to bed and when they awoke during the night was commonly reported. During this time, they usually thought about the past, their daily life problems, and the possible consequences of not sleeping that could occur the next day. Despite experiencing intrusive thoughts that prevented them from falling back to sleep, they would try to relax and not to obsess over the situation.

Desperation and anticipation of poor sleep quality

It was common for participants to experience frustration and despair at not being able to sleep, which could even lead them to think about suicide. One woman reported that the impact of her pain on her sleep was so unbearable that she would cry out of anger. It was identified as a possible process of anticipation of a sleepless night, as they reported knowing or feeling when they were going to have difficulty sleeping.

Future expectations

The participants expressed differing beliefs regarding the consequences of poor sleep quality in the future. Some women were not worried about the future and believed that their sleep could be managed and improved, whereas others were convinced that the quality of their sleep would worsen over time, which had a significant impact on their health status.

3.2 | Poor sleep quality management strategies

3.2.1 | Management strategies suggested by health care professionals

Health care professionals' awareness of sleep in the context of FM

It was common among participants to report that they never received information about sleep problems related to FM, even when they complained about sleep problems during a medical consultation. Only one woman reported being informed about sleep disturbances related to FM by her health care provider (a psychologist). Consequently, participants used the Internet and attended seminars to learn about sleep in the context of FM.

Self-management advice from health care professionals

In general, women diagnosed with FM believed that they did not receive enough information from health professionals about strategies to effectively manage poor sleep quality. Examples of health professionals' recommendations were to have a light dinner, to use the bed only for sleeping, and to not watch television or use electronic devices at night. However, one of the women stated that she did not follow the advice because she believed that general recommendations are not always useful for everybody.

Pharmacological treatment as the main approach

The participants generally believed that health professionals preferred to treated poor sleep quality through pharmacological methods. Medications prescribed to improve sleep included sleeping pills, antidepressants, and anxiolytics. Participants were divided among those who mentioned that the medication was effective and helped them to fall asleep quicker and sleep longer, and those who found medication to be ineffective. The first group of women explained that taking sleeping pills helped them to sleep for at least a few hours straight and to wake up feeling more refreshed. Taking antidepressants or anxiolytics made them feel relaxed and allowed them to fall asleep quicker. However, there were also women who recognized that they became dependent on their medication because they assumed that they would not be able to sleep without it. These women worried about the possibility of needing stronger medication in the future.

The second group of women refused sleeping pills and antidepressants, and tended to also refuse other medications, such as pain killers, because their taking these medications had not resulted in better sleep. For these women, the medications had only been effective at the beginning of use or for a short period of time, the effects did not last throughout the night, and there were negative side effects (e.g., general discomfort, feeling drugged, or paresthesia in the extremities). In addition, these women worried about the long-term effects of the medications. It was common among these women to take medication only as an exception, as a last resort when they felt desperate.

3.2.2 | *Self-management strategies*

General strategies for improving sleep quality

Although taking melatonin, performing mindfulness techniques, and undergoing acupuncture were generally considered effective strategies, taking valerian supplements did not help to improve sleep quality. Other strategies mentioned were engaging in physical activities during the day (e.g., walking), avoiding naps, not drinking coffee, or limiting the intake of coffee after noon, trying to feel tired at night, using articulated beds or cervical pillows, and having a daily scheduled routine. However, strategies tended to work one day but not the next, making it difficult to cope with poor sleep quality.

Strategies for falling asleep and for dealing with interrupted sleep or waking up too early

The strategies employed to induce sleep when going to bed were watching television or using the computer or laptop, although participants recognized that these actions contradicted professional

recommendations. They also counted sheep, prayed, or used painkillers or topical ointments to relieve pain or to induce relaxation. One strategy employed by participants who were waking up too early in the morning was to rearrange their sleep schedules in order to go to sleep later.

When dealing with difficulties falling asleep at the beginning or during the night, two differing main strategies emerged: getting out of the bed and staying in the bed. However, the participants recognized that neither strategy was effective for preventing waking up in the middle of the night. During their time awake, instead of or in addition to taking medication, the participants usually employed relaxation techniques to avoid overthinking and worrying, such as listening to music or the radio, and/or drinking a hot beverage.

Coping with the consequences of poor sleep quality during the day

Participants usually coped with poor sleep quality at night by napping, resting and relaxing, drinking coffee or tea, and/or taking energy supplements, such as ginseng, during the day. Nevertheless, some participants recognized that some of the strategies could negatively affect their sleep at night, and that they could still have trouble falling asleep despite feeling tired, whereas others tried to continue performing their daily activities without a concrete compensating strategy.

Needs

Participants missed the sleep quality that they once had and/or envied those who had no sleep problems. They were motivated to improve their sleep, obtain more knowledge about sleep problems in the context of FM, receive more information from health professionals about effective self-management strategies, and obtain prescriptions for medications that could improve their sleep (e.g., assist them in falling asleep or allow them to sleep longer without interruption).

4 | DISCUSSION

In the present qualitative study, the main sleep problems reported by women diagnosed with FM were those related to the initiation and maintenance of sleep, and inadequate total sleep time. They did not receive information from health care professionals about sleep in the context of FM or about how to effectively manage their sleep problems. They reported the treatment approach of most health professionals to be mainly pharmacological and unsatisfactory. Consequently, women resorted to improvised self-management strategies to improve their sleep, which were also ineffective or even detrimental to their sleep.

The SMT provided a well-founded framework to conceptualize poor sleep quality in the context of FM from a biopsychosocial perspective. Integrating the domains of "symptom experience," "management strategies," and "outcomes" of the theory helped to comprehensively understand how women diagnosed with FM evaluate and respond to poor sleep quality, how they manage this symptom and their perceptions of the treatment approaches provided by health care professionals. Likewise, the SMT provided guidance to identify the needs of women diagnosed with FM to develop effective management strategies to cope with poor sleep quality.

The results of this study support those of previous studies in which the participants reported that the main sleep problems experienced were difficulty falling and maintaining asleep, and constantly waking up during the night (Theadom & Cropley, 2010). In fact, sleep disturbances are usually perceived as the worst symptoms of FM and a betrayal of the body (Cudney et al., 2002; Sturge-Jacobs, 2002; Theadom & Cropley, 2010).

The participants also mentioned other sleep problems that could be indicative of sleep apnea syndrome. İnönü Köseoğlu et al., (2017) observed that obstructive sleep apnea is considerably prevalent among people with FM, and that it is correlated with greater intensity of pain and severity of FM.

Similar to a previous study (Theadom & Cropley, 2010), symptoms of restless leg syndrome were also reported by our participants. Restless leg syndrome negatively affects sleep quality and quality of life in patients with FM, and some antidepressants commonly prescribed to these patients (e.g., fluoxetine, sertraline, and amitriptyline) may increase limb movement (Kolla et al., 2018).

Our results confirmed the existence of two differing attitudes toward medication in FM patients: dependency and rejection. Not taking sleep medication leads to not being able to fall asleep (Arnold et al., 2008; Crooks, 2007; Cudney et al., 2002; Theadom & Cropley, 2010) and patients usually complain of not having the tolerance level for the majority of drugs to treat insomnia, which makes them susceptible to the more common side effects, including falls and cognitive disturbances (Hemati et al., 2020; McCrae et al., 2020; Rico-Villademoros et al., 2020; Sallinen et al., 2011). Attitudes of rejection toward sleeping medications are primarily due to their short-term effectiveness or lack of effectiveness (Theadom & Cropley, 2010). A recent article in Spain demonstrated that patients with FM are unsatisfied with the pharmacologic treatments received because these treatments do not provide clinical benefits even when the patient is overtreated (Hemati et al., 2020; Rico-Villademoros et al., 2020).

Participants in this study attempted to find a balance between medication benefits and side effects. For example, some took melatonin or valerian supplements. The available evidence shows a positive effect of melatonin on FM symptoms (Hemati et al., 2020). Similar to other studies, one strategy used by the participants was to take medication occasionally, as a last resort only when they felt it was absolutely needed, and even if the medication caused side effects (Lempp et al., 2009). For example, taking painkillers during the day could allow them to perform activities of daily living without pain (Cunningham & Jillings, 2006), and painkillers can help participants to fall asleep during the day (Söderberg et al., 2002).

With regard to self-management strategies used by participants, some were in line with the principles of cognitive-behavioral therapy for the treatment of insomnia, such as establishing regular sleep schedules, obtaining physical exercise, practicing relaxation techniques, avoiding naps, and not drinking coffee after noon (Morin

et al., 2017). Although organizing regular sleep schedules is a common strategy, it is known to generate anxiety (Raymond & Brown, 2000; Theadom & Cropley, 2010). One strategy that emerged in our study that has not been reported in previous studies was using cervical pillows or articulated beds to reduce pain during the night.

Getting out or staying in bed were the two main strategies for returning to sleep when experiencing awakenings during the night, and one previous study indicates that patients could try to avoid developing attitudes of rejection toward the bed when they got out of bed (Theadom & Cropley, 2010). However, our results identified other strategies not found in previous literature, such as watching television, listening to music or the radio, using the computer, avoiding overthinking, drinking a hot beverage, praying, and applying topical ointments for pain.

Daytime rest and relaxation came up as a strategy to cope with the consequences of poor sleep quality. This finding was in line with those of previous qualitative studies (Crooks, 2007; Cudney et al., 2002; Söderberg et al., 2002; Theadom & Cropley, 2010). In this study, participants also mentioned drinking stimulants and taking ginseng to perform their activities of daily living with more energy.

Participants reported that physical activity acted as a moderator of sleep quality. In line with our results, Borges-Cosic et al., (2019) revealed that women diagnosed with FM who showed lower sedentary time and greater engagement in daily physical activity had better sleep.

With regard to beliefs about the cause of their sleep problems, the participants mentioned aging, menopause, and stress, among other factors. It has been observed that aging is related to dysregulation of neurotransmitters implicated in the regulation of sleep-wake cycles, such as orexin, adenosine, galanin, and serotonin, a degeneration of the white matter, and a dysfunction of the suprachiasmatic nucleus, which could lead to sleep disturbances (Zhong et al., 2019). In this study, the participants perceived that the initiation of their sleep problems coincided with menopause. A recent systematic review found that in 65% of the cases, FM is diagnosed after menopause and that sleep problems linked to menopause may be predisposing factors for the development of FM. The rapid hormonal decline after surgical menopause is also associated with FM symptoms, including poor sleep quality (Dias et al., 2019).

Although the role of stress as an underlying mechanism for developing sleep problems in the context of FM is still open for scientific debate, high levels of perceived stress are correlated with greater sleep disturbances and poorer daily function in patients with FM (Theadom & Cropley, 2008).

Similar to this study, other studies have demonstrated that poor sleep quality is also perceived as negatively affecting other symptoms of FM, such as pain, fatigue, and cognitive function (Crooks, 2007; Cudney et al., 2002; Cunningham & Jillings, 2006; Lempp et al., 2009; Martin et al., 2009; Ramlee et al., 2016; Theadom & Cropley, 2010). Available scientific evidence (Keskindag & Karaaziz, 2017) indicates that pain and sleep interact in a bidirectional manner; patients with greater pain intensity experience more sleeping problems, and vice versa. However, one previous study suggests that poor sleep quality affects pain more than pain affects sleep (Choy, 2015). Additional consequences not found in this study include changes in eating behaviors (Martínez-Rodríguez et al., 2020; Ramlee et al., 2016), symptom flare-ups (Vincent et al., 2015), and an impaired ability to manage other symptoms (Theadom & Cropley, 2010). Participants in this study reported that poor sleep quality also worsens stiffness, quality of life, and general health status, which were not observed in previous qualitative studies. Because of these negative consequences, sleep problems affect the functional capacity of patients with FM in the workplace, which causes them to experience anxiety and a feeling of constant failure (Theadom & Cropley, 2010).

It is well understood that poor sleep quality generates negative responses, such as feelings of helplessness, despair, and frustration (Cudney et al., 2002; Kleinman et al., 2014; Theadom & Cropley, 2010); the this study adds to the previous knowledge that not being able to sleep can even provoke suicidal thoughts. Participants in other studies expressed hatred toward their health condition, and the inability to satisfy their sleep needs was a major contributing factor to this feeling (Cudney et al., 2002). Previous studies have also demonstrated fear of not sleeping or even going to the bed (Sturge-Jacobs, 2002; Theadom & Cropley, 2010). The original contribution of this study is related to catastrophic thoughts regarding the consequences of poor sleep quality in the future. In line with our results, other studies have demonstrated that it is common among patients with FM to be resigned to sleep disturbances (Sturge-Jacobs, 2002). This attitude could be used by patients as a strategy to cope with FM limitations (Briones-Vozmediano, 2016; Briones-Vozmediano et al., 2016).

One of the main findings of this study is that participants expressed the need to receive more information about sleep in the context of FM and advice on how to manage poor sleep quality. The latter can explain why patients with FM look for information on the Internet or other sources of information that may be unreliable and negatively affect how they manage poor sleep quality. In this regard, the European League Against Rheumatism recommends patient education as an initial approach to the management of FM (Macfarlane et al., 2017). However, education interventions for sleep problems are very limited in chronic pain management programs (Tang et al., 2015).

Patient education about sleep should be an essential part of the treatment of FM and, therefore, health care professionals should include this education in their daily clinical practice (Lewis et al., 2019). However, carrying out education interventions in medical consultation is, in most cases, nonviable, given the evident time restraints that accompany health care practice (Baird et al., 2016; Irving et al., 2017). Web-based education interventions could be useful tools for educating patients without consuming time during consultations (Climent-Sanz, Gea-Sánchez, et al., 2020).

A critical examination of the principles and practice of qualitative research is provided in this book, which examines the interplay between context and method, making it invaluable for both the experienced and the beginning researcher. A range of methodological and practical issues that are central to the concerns of qualitative

researchers are addressed. These include the validity and plausibility of qualitative methods, the problems encountered using specific techniques in a range of social settings, and the moral issues raised in qualitative research. These themes are related to practical issues, which are illustrated by a breadth of examples and in-depth case studies. The contributors look at the methods and strategies that they have used to study everyday life and make suggestions to readers on why and how they...

4.1 | Limitations and strengths of the study

This study had one major limitation. We were unable to collect some sociodemographic data such as the number of children and the medication that each participant had been prescribed for sleep problems, because in some cases the interviewed women did not remember the drugs' names.

The strengths of our study include that our data were recently collected (January–March 2020) and the triangulation of data interpretation among researchers with different profiles (physiotherapy, nursing, public health, and gender studies). Several techniques were used to avoid possible biases in the analysis and interpretation of the data, which are inherent to the qualitative process and could be a limitation of the study. Among them, (a) the supervision and audit of several researchers not directly involved in the analysis and interpretation, (b) the coding, analysis, and interpretation conducted by two researchers independently, and (c) the detailed description and contextualization of the entire process for the readers' evaluation.

5 | CONCLUSIONS

This study demonstrated that women with FM need nurses and other health care professionals to provide them with more information about sleep in the context of FM and on how to effectively cope with poor sleep quality and its consequences.

As education emerged as an essential need for women diagnosed with FM to cope with poor sleep quality, our results could impact on both the research and the clinical levels in helping the development of patient-centered educational materials focused on the improvement of poor sleep quality management. Future research, either qualitative or quantitative, should investigate which factors influence the development of certain self-management strategies to cope with poor sleep quality. In addition, exploring the health providers' perspectives on the management of poor sleep quality in people diagnosed with FM could also provide important information on the facilitators and barriers that they find to implement effective management programs for the treatment of poor sleep quality in their FM patients. Although FM is a condition mainly diagnosed in women, further research could explore the construct of poor sleep quality in men suffering from this health condition.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTION

CCS, MGS, HFL, EBV: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; CCS, MGS, HFL, JTMG, FRC, EBV: Involved in drafting the manuscript or revising it critically for important intellectual content; CCS, MGS, HFL, JTMG, FRC, EBV: Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; CCS, MGS, HFL, JTMG, FRC, EBV: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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